

Getting Started and Sticking to a Plan!!!

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Exercise is:

SAFE **EFFECTIVE** VITAL IN REDUCING DISEASE DAMAGE UNDER YOUR CONTROL FLEXIBLE TO YOUR NEEDS



Inhibitors to Exercise Programmes

- **FEAR**
- Weakness
- Reduced movement
- Reduced mobility
- Pain
- Fatigue
- Mood
- Self-Belief / Self-doubt
- No idea how to start!
- Understanding yourself





Knowledge



- Belief in Exercise
 - Self belief
 - Understanding of change in medical belief
- Fear of Exercise
 - Will I do more harm?
 - Am I safe to do the exercises?
 - Where do I start?

Philosophy

Your disease belongs to you.

If YOU can control my disease Then I can use my body

If I can control my Disease then can use my body

However

- What about pain?
 - What does it mean?
- What if I do some harm to myself?
- I am scared and I don't know where to start with exercise

PAIN and FEAR can really inhibit progress and participation

Definition of Pain

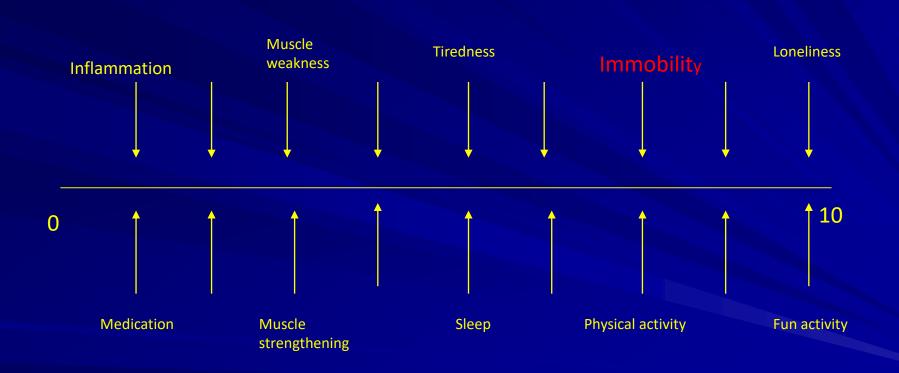
A negative sensory and emotional experience

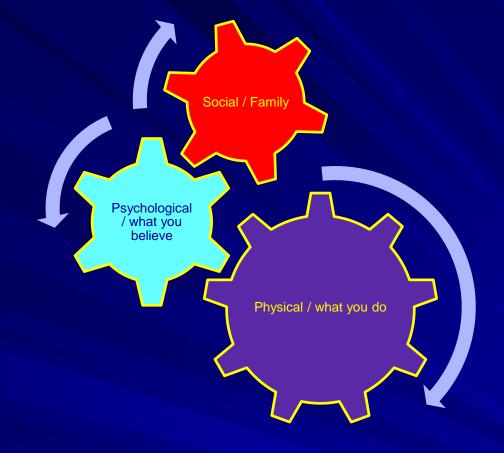


Managing pain together – improve disease control

- American Pain Society (2012)
 - Improve all domains of functioning and quality of life
- For you and your family
 - Facilitate change in relationship to pain/disease
 - Optimise quality of life
 - Increase function despite pain / disease
 - Facilitate adoption of self-management approach
 - Enhance well-being

Complexity of Pain / Loss of Function





BIO-PSYCHOSOCIAL MODEL OF MANAGEMENT

Obstacles to effective self-management/recovery

Bio

Complex condition,, changeable presentation, effectiveness of treatment, receptiveness to recommendations, biomechanical compensations, unclear prognosis,

functional impairments,

Psych

Anxiety re treatments/prognosis,
low mood
reduced function
social isolation,
family members anxiety/low mood,
family coping strategies,
Pain management,
adjusting to environment/
condition/function,
motivation,
helplessness

Social

poor work attendance (social isolation),
family dynamics/discord,
roles (sick role),
reduced activity based interaction with peers,
Supporting the family,
partners employment,
any welfare concerns,
recommencing work,
social support services locally

Approaches to managing obstacles

Bio

Physiotherapy: rehab, retraining muscles, normal movement patterns and range of movement, function/mobility

OT: encouraging appropriate ADLs

Function despite pain

Pacing eep hygiene

Group Rx sessions Graduated return to work

relationship difficulties

Social Vork devise a paced, graded return

Support to enable partner to access their own pain management intervention and return to ork/alternative role outside 'carer'

Encouraging enjoyable interaction with others apport partner through understanding of pain to increase function

Psycho

Active Relaxation

Distraction

Stress management (goal setting, communication, time management...)

Psychological Therapy options:

Cognitive behaviour therapy (inc. graded expos to overcome fear avoidance, cognitive restructur to address anxiety)

> Mindfulness based approaches Acceptance and commitment therapy

Things that Increase Pain and Loss of Function

- Immobility / Rest
- Focusing on the Pain
- Fatigue
- FEAR
- Negative thoughts/feelings/emotions
- Muscle weakness/loss of stamina
- Abnormal movement patterns



Things that decrease the Pain and Improve Function

- Exercise / Movement
- Distraction



- ■Sleep
- Confidence
- Good muscle strength
- ■Normal movement patterns





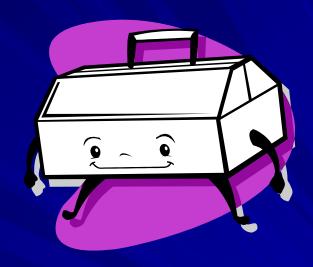


Comfort Tool Box

- Exercises and physical activity
- Distractions
 - Games
 - Crafts
 - Movies
 - Reading
- Going to work
- Positive statements
- Coping statements
- **Imagery**

 - Safe/happy placeChanging the pain image
- Relaxation

 - Guided Imagery
 Progressive Muscle Relaxation
 Controlled Breathing
- Comfort items (marbles/ velvet etc)
- Self hypnosis
- Hobbies/activities
- Friends and families
- etc



Find reasons to do exercises and activity

NOT reasons not to do them!







Positive Approach

- Improve mood
- Increased energy
- Less pain
- More activity
- More determination
- More positive solutions
- More mobility
- Dedication to treatments exercise and meds.

"A positive attitude brings strength, energy, motivation and initiative."





Partners as coaches

- Encouraging
- Supportive
- Confident
- Enthusiastic



Taking care of themselves







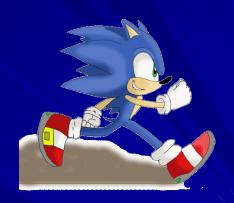
Emotional Affects of Exercise



- Confidence
- Self Esteem
- Inclusion



- Group Physio Sessions
- Group sport / training
 - Care is needed to ensure inclusion and not exclusion!



Simple vs Complex Exercise

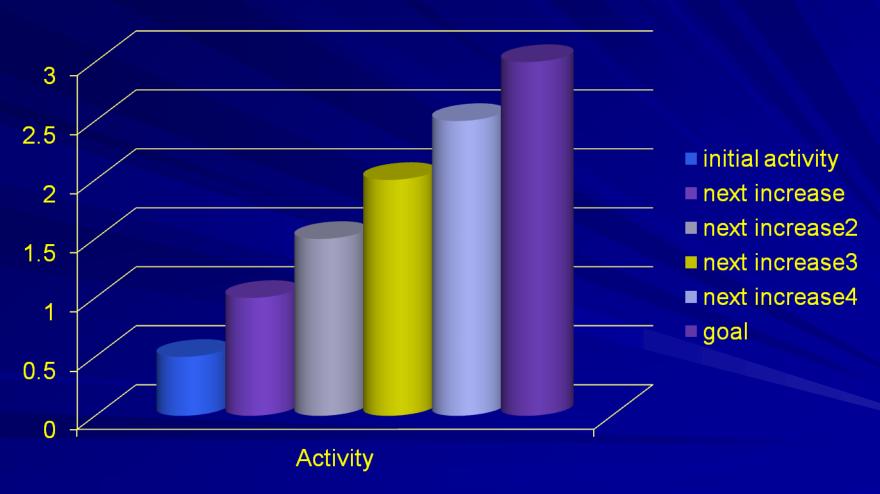
- Complex exercise (General fitness)
 - Walking
 - Running
 - Football



- Simple Exercise (Correct biomechanics)
 - Hip abduction
 - Straight leg raise



Starting to exercise with a paced approach



Set goals

- Specific short and longterm
- Measurable
- Attainable should be important for you
- Realistic
- Timely set a time frame for when you want to reach the goal

■ Set new goals – exercise diary

Consistent Pacing

On GOOD days do not do more

On BAD days do not do less

Changing the focus of myositis in your life.

■ Write lists:

- What you would like to do in your life?
- What is stopping you achieve this?
- How are you going to overcome these issues?
- What do you need to overcome these?
- Who do you need?

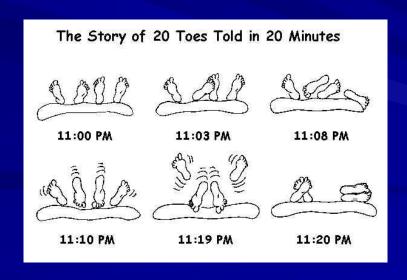
Example:

- I want to walk the dog:
 - Too much pain in my legs
 - My muscles are too weak
 - I get out of breath easily
 - I am nervous the dog is going to pull me over
 - I am nervous about going out on my own

(How / what / who!)

Activities in daily life

- Most affected
 - Activities of moving around (walking, running, walking stairs, public transportation)
 - Work
 - Leisure activities sex life/intimacy important



Tools to stay on track

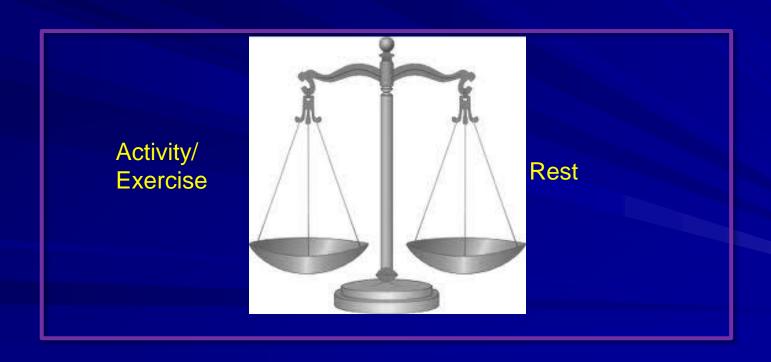
- Exercise diary
- App run keeper or similar
 - Keep track on changes in function and exercise activities
- Have contact with a physical therapist to assess your function and develop your exercise
- Local myositis support group exercise together with others with myositis
 - Help each other to stay on track

What if I fall of the wagon?

- Start again find activities you enjoy
- Set new goal start doing something and increase slowly – weekly/monthly – longterm target
- Don't try to do too much too soon
- Get support from family, friends

How to improve activity

- Ergonomics
 - Less energy



Assistive devices and ergonomically smart things

Assistive devices

Compensatory

Eronomic/energy saving





Assistive devices and ergonomically smart things



Wrist splint





Dorsal flexion



http://camp.se/fot-och-fotledsortoser/toeoff -familjen/navigaittm.html







Swedish Ankle Foot Orthosis
http://www.rehabmart.com/product/swedish-anklefoot-orthotic-252.html (57USD)

Knee orthosis





http://www.shutterstock.com/pic-305349119/stock-photo-anatomic-knee-orthosis-elastic-dressing-knee.htlm

Conclusion

- Active participation in managing your disease
- Exercise is vital in the management of myositis
- Find effective pain management techniques
 - Distraction
 - Active relaxation
- Improved function
- Alter focus/thoughts about exercise
- Mindfulness

Exercise and physical activity

- Talk to your neighbor- how do exercise and why?
- How did you get started and maintaining?